

My testimony is against cuts to DDS funding.

I'm a single mom, a Senior Citizen now, 65, and expected that my 4 severely disabled adult sons whom I adopted would have DDS residential placements by now. Three of them do, living in community residences and attending day programs funded by DDS. But my 4th son, Patrick, most disabled of all, was left on the DDS residential wait list, Priority 1. And he's still waiting.

Patrick, 34, is not only intellectually disabled, but quadriplegic, blind, epileptic, and medically fragile. He has a G-tube, J-tube, and a Central IV port. He chronically aspirates, resulting in pneumonia, even Life-Star flown twice. Patrick has a trach (artificial airway) which must be suctioned to clear secretions and monitored for blockage, so he requires round-the-clock nursing. He is also on oxygen now.

Patrick had only 40-50 hours a week of nursing, and I did the remaining hours, the equivalent of 3 full-time jobs, sleeping only 2-4 hours a night.

When I was diagnosed with the beginnings of macular degeneration and cataracts, I again asked for a DDS placement before my vision becomes blurry. "Not until you go blind," I was told !

In October the bottom fell out. Patrick lost his only full-time nurse, with no available replacement. I was now doing 150 hours a week of care, almost 4 full-time jobs. Without his nurse, he was also no longer able to attend the day program which he loved.

Incredibly, when DDS met he was NOT reclassified from P1 to Emergency. There was no funding for him. And because of ongoing cuts to DDS, there wasn't even one residential vacancy in the whole state of the kind Patrick needs ...an ICF home with round-the-clock nursing like his younger brother lives in. That's because private providers don't have the needed DDS funds to create new ones.

In November, Patrick was accepted into the Hospital for Special Care, Respiratory Step Down Unit, a sudden move with no transition. Patrick was placed in a 4-bed hospital room crowded with patients and medical equipment. This is only an INTERIM placement, however, and Patrick is still on the DDS residential wait list. After living a rich family life, fully included in public school, participating in Scouts and soccer with his peers, Patrick should not be warehoused in a hospital where his joy of living diminishes each day. He should be living in a residential home with friends, activities, and loving staff who are like family and have time to interact with him. He should have the opportunity to go out to a day program again. None of this will happen with funding cuts to DDS !

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